Dignity in dying
your life, your choice

NEWS

ISSUE 9, AUTUMN 2008

Peers, MPs and supporters gather in Parliament

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Dignity in Dying's mission:

- Patient choice at the end of life
- A dignified death for all

Dignity in Dying strongly supports good palliative care

Dignity in Dying is also the leading supplier of advance decisions in the UK

Dignity in Dying is supported entirely by voluntary contributions from private individuals and is independent of any political, religious or other organisation.

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The views expressed in this magazine are not necessarily those of Dignity in Dying, but may be those of individual contributors.

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Sarah Wootton, Chief Executive

Welcome to the Autumn edition of Dignity in Dying News. We have had an exciting few months with the launch of our Charter for Dignity at the End of Life. The Charter received positive press coverage and chimed with many of the promises made in the Government's recently released End of Life Care Strategy. On page four, we highlight the steps that need to be taken to make these promises a reality. We are also asking you to write to your MP about our Charter.

Choice at the end of life also gained a huge amount of publicity from Debbie Purdy's case in June. Debbie challenged the Director of Public Prosecutions to issue a policy on whether family and friends will be prosecuted if they help someone to travel to a country where assisting a suicide is legal. The landmark Judicial Review will take place in October and should clarify the law. We hope that it will give families and friends peace of mind in the future, as people who accompany loved ones overseas to die are still being threatened with prosecution. Read about Debbie's battle on page three.

Our campaign gathered support in Parliament when the All Party Parliamentary Group on Compassion in Dying held a special event, attended by MPs and Peers, bringing together families who have travelled abroad to help their loved ones. Read about the meeting on page six.

We are looking forward to an even wider gathering of supporters at our AGM, which will feature guest speaker, Esther Rantzen. The meeting will give us all an opportunity to share experiences, learn from each other and further our campaign. Please let us know if you are attending. Members will find more information on the AGM and Board elections enclosed with this newsletter.

After a busy Summer it looks like Autumn will be equally exciting and eventful. Please keep up the pressure on your MPs and let us know about any responses you receive. Even a negative response can lead to positive outcomes for the campaign - as Lisa Cook's story on page eight shows. Please also look out for any letters, blogs or websites opposing our campaign - we need your help to monitor and counter the opposition - see page twelve.

Things are moving forward - the End of Life Care Strategy shows that the Government does recognise that people want and need more choice and better care at the end of life. That is a huge step forward in itself. Together we will achieve our aim of ensuring that everyone has what they consider to be a dignified death.

Sarah Wootton

Debbie wins Judicial Review

Campaigner Debbie Purdy has won the right to have her case heard by a Judicial Review in October. This could lead to a new policy being issued on the law surrounding anyone who accompanies another person abroad to have an assisted death.

Debbie, 45, from Bradford, who suffers from primary progressive Multiple Sclerosis, wants to travel to Dignitas, in Switzerland, to end her life when her suffering has become unbearable. She wants her husband, Omar Puente, to accompany her. However, she states: "I do not want to die knowing that there is a chance my husband could be prosecuted on his return to the UK."

Currently, Omar could be liable to prosecution and a prison term of up to 14 years if found guilty of assisting, aiding or abetting a suicide. However, none of the relatives, who have accompanied the 92 Britons who have already been to Dignitas, have been prosecuted on their return to the UK. Many have been questioned by police and had to wait several months before their case has been dropped.

Sarah Wootton, Chief Executive of Dignity in Dying, said: "We are relieved that the Court has made this decision in Debbie's case. We hope that common sense prevails and the Judicial Review will clarify the law, so that people considering travelling to Dignitas will know where they stand."

The decision hit the headlines with Debbie being interviewed on the main news channels as well as BBC Radio 4's Woman's Hour and Five News. Press coverage included interviews with The Guardian, The Independent, The Daily Mail, The Sunday Telegraph and Grazia, Yours and Chat magazines.

She was quoted in Grazia as saying: "Looking up at the walls of the High Court, I wondered how I had ever come this far. I'm just an ordinary woman and yet I was asking the most influential judges to look at the law."

> "I am delighted that the courts have decided to officially review the law surrounding my case."

About Dignitas

- Dignitas has been open since 1998
- The clinic has helped 868 people to end their lives
- 92 of these people were from the UK*
- 17 people from the UK travelled to Dignitas in 2007 to end their lives
- 8 British people have had an assisted death at Dignitas so far in 2008*
- Dignitas has 694 members in the UK

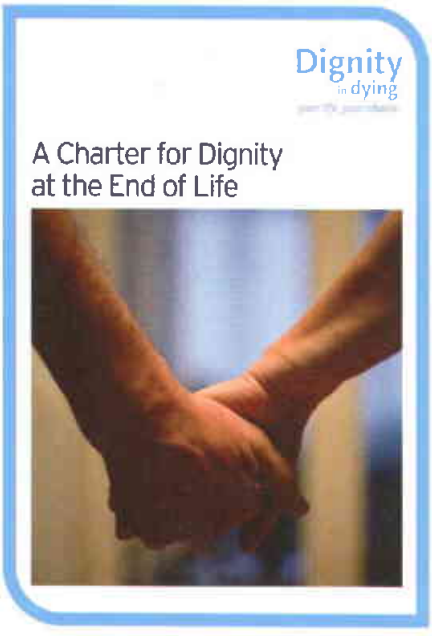
* As of June 2008

Prosecuting policy

The purpose of a prosecuting policy is to give guidance to the police and crown prosecutors on how to interpret and apply the law in a given area. The DPP has issued prosecuting policies on several areas of the law including domestic violence, drink driving, race and disability hate crime.

Stand and deliver

Our Charter for Dignity at the End of Life, released in June, highlighted the need to give people greater choice, control and access to high quality palliative care at the end of life.



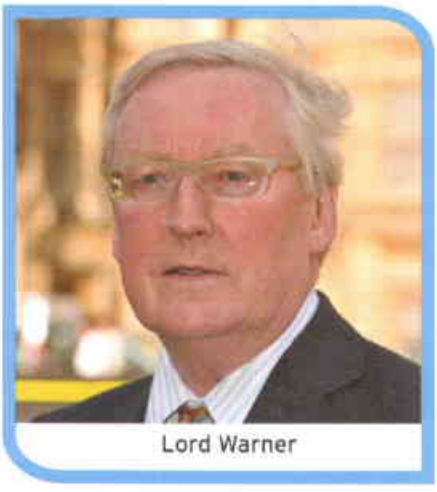
The Charter calls for assisted dying to become legal, which is supported by over 80 per cent of the population. We also call for the registration of advance decisions, as we believe registration is vital for advance decisions to work properly, and better funding for and access to palliative care.

We think it is vital that palliative care is extended and improved and assisted dying is made legal: both measures are needed to give people dignity, as different people have different beliefs and ideas about what makes a dignified death.

Lord Norman Warner, former Health Minister, wrote the foreword to the Charter.

> "The Charter for Dignity at the End of Life places choice, access to services and personal control at the heart of improvements to end-of-life care."

He says: "I hope that its recommendations will be carefully considered by the providers, policy decision-makers and users of our much valued and treasured National Health Service."


Lord Warner

Chief Executive of Dignity in Dying, Sarah Wootton, points out in the introduction to the Charter that there is a serious disconnect between what people expect at death and the services that are currently available. A poll commissioned by Dignity in Dying found that 72 per cent of people are shocked that palliative care is only routinely available to cancer patients and not to those with other terminal illnesses. The survey also found that 79 per cent believe it is important not to have their lives prolonged against their wishes.

The Charter sets out what needs to be in place to make dying with dignity a reality in ten key points, summarised below:

1. Everyone should have the opportunity to create an End-of-Life Care Plan.
2. Health professionals should have a duty of care to consider these plans.
3. Government should promote awareness of Advance Decisions.
4. Advance Decisions should be recorded on a national health register.
5. Parliament must give terminally ill, mentally competent adults the right to an assisted death.
6. More resources should be made available to palliative care.
7. The postcode lottery in accessing palliative care should end.
8. A Carers' Benefit should be introduced for all those providing 35 or more hours care each week.
9. Health and social care professionals should have access to training on end-of-life issues.
10. Bereaved people should have easy access to professional advice.

Please write to your MP about our Charter

James Harris, Head of Campaigns at Dignity in Dying says:

"It is crucial that the Government incorporates our Charter's values of patient choice, control and access to services at the end of life. The Government's End of Life Care Strategy is a good start – but we need to ensure that good policy becomes good practice.

In June, all Parliamentarians were sent a copy of our Charter. Please write to your MP to ask them for their views on our Charter and its aims, and update us on any feedback you get. With your support we will bring about change".

To email your MP or to locate their contact details please visit: **www.theyworkforyou.com**

James Harris

Government promises more choice

The Government published its own End of Life Care Strategy in July. The End of Life Care Strategy focuses on improving the quality of care people receive at the end of life and giving people more choice about where they die.

Sarah Wootton was interviewed on ITV News about the Government's End of Life Care Strategy. Here she shares some of her thoughts.

On paper, the Strategy is a significant step forwards, and we are delighted that many of the proposals in our Charter for Dignity at the End of Life look set to be implemented. However, delivery and implementation are vital if the Government is to ensure that people's legitimate expectations of choice, control and access to services at the end of life are met by reality. It is absolutely vital that terminally ill patients are given the opportunity to express their preferences around end-of-life care, and that these are recorded and, wherever possible, respected. Consequently, Dignity in Dying welcomes the emphasis on care planning in the Strategy and the announced measures to support people to die in their place of preference.

We also welcome plans to ensure that carers are appropriately supported both during a patient's life and after bereavement, and that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care. We are pleased the Government has acknowledged the need to increase public awareness and discussion of death and dying – as this will encourage individuals to discuss their own preferences around end-of-life care.

It is now time for good theory to become good practice.

Responsibility for delivering the End of Life Care Strategy rests with the individual trusts. All individual trusts will need to buy into this Strategy in order to achieve universal access to good quality care at the end of life. The Strategy states that quality standards and other mechanisms for measuring the progress made with the implementation of the Strategy are currently being developed. These will need to be put in place as soon as possible in order to measure the progress made in improving the delivery of end-of-life care.

We look forward to improvements in end-of-life care, across all settings and for all patients, regardless of their condition or the place people live. It is time for the postcode lottery in accessing good quality end-of-life care to end.

The care pathway

A key theme of the End of Life Care Strategy is the concept of care pathways for people approaching the end of life.

The care pathway for an individual would involve:

- Identification of people approaching the end of life and initiating discussions about preferences
- Care planning
- Coordination of care
- Delivery of high quality services in all locations
- Management of the last days of life
- Care after death
- Support for carers

Meeting of like minds in Parliament

Family members who have travlled to Dignitas in Switzerland, MPs, Peers and other supporters gathered together in the Houses of Parliament in June.

The event, called 'Travelling Abroad to Die - the People Behind the Headlines', was organised by the All Party Parliamentary Group on Compassion in Dying, which supports Dignity in Dying's campaigns.

Two of our leading campaigners, Lesley Close and Debbie Purdy, gave very moving speeches at the event.

Lesley Close

Lesley told the story of her brother, John's, decision to go to Switzerland to be assisted to die.

"Before my brother developed Motor Neurone Disease, he was a fit, creative and funny man who ran marathons, wrote songs and told jokes.

In March 2001, John was diagnosed with MND. By the time he died, John couldn't do very much on his own. He couldn't stand, sit up unaided or turn over in bed and his speech was reduced to grunts and aspirations. He needed help to get dressed, to move between his wheelchair and the shower, to wash his body, and with feeding and getting in and out of bed.

Lesley and John

The story of Reg Crew's journey to Dignitas caught his imagination. I had mixed feelings. We'd both known since diagnosis that he would die prematurely but confronting the reality was still very sad. But my main feeling was an overwhelming sensation of relief that John might have found a safe and reliable way out of what was becoming an intolerable situation for him.

I'd seen what happened to Win Crew. Within a few days of her husband's death, she was back in this country under investigation by the police. But I couldn't let that stop me. It would have been impossible not to help my brother with something so fundamental. When I was feeling brave I knew that, legal or not, I would do whatever it took to help John. He knew what he wanted and I'd promised to help him achieve it.

In May 2003, we travelled to Dignitas. The journey was difficult for both of us but it was bearable because we hoped it would culminate in what John wanted more than anything, a peaceful

John and Lesley in 1975

release from the intolerable burden that his life was becoming for him. If that same assisted death had been available at home, John could have lived a little while longer.

John did achieve his goal of a good death but he died not knowing if I faced prosecution for helping him to achieve it. For weeks after I returned to the UK I expected the heavy hand of the law to fall on my shoulder, questioning me about my role in aiding and abetting John's suicide. John had been very worried about the possibility that I might be prosecuted for helping him to die but I told him that he needn't worry, that I wasn't concerned about what might happen to me. That wasn't strictly true, but I didn't want to give John any more anxiety before he died.

The British Government is failing to meet the needs of some of its terminally ill citizens. Not all terminally ill people who want help to die are physically able to make the

journey to Switzerland. Not everyone can afford that journey. No one should be forced to leave Britain simply in order to die with dignity.

With proper medical assistance for people who want it, we have the potential to take away the fear of death and make dying a dignified and peaceful experience for the person who is dying as well as for their watching loved ones."

Debbie Purdy

The meeting in Parliament took place just days after Debbie's Permission Hearing, so she was able to update attendees on her case.

"My case will be back in court in the Autumn as judges have given permission for a Judicial Review of the law around assisting a suicide, in countries where it is lawful.

If the Department of Public Prosecutions (DPP) does clarify that my husband will not be prosecuted for accompanying me overseas to die, I will be able to wait until I'm ready to go. I want to wait until the last possible moment. However, I cannot do that while there is a chance my husband will be prosecuted. If the DPP does not give this assurance, then I would need to go to Dignitas a long time before I want to die.

I'm not doing this because I want to die - I love life. But I do want to know where I stand under the law. I do want peace of mind. In Oregon in the USA, where assisted dying is legal, only 1 out of 20 people who make a request to die actually go on to have an assisted death. Knowing they have the option of choice allows the majority of people to keep going. I am not doing this because I feel I am a burden. My husband and I love each other very much. He helps me with the things that my MS stops me from doing unaided, and I help him manage bookings and so on for his work as a musician. I am doing it because I want to be able to choose when my suffering has become too much to bear. But I don't want to make a choice that will cause Omar to suffer - I don't want him to go to prison for his own sake and that of his family.

I am mentally sound and I know what I am doing. I am trying to ensure that I have choice and my husband is safe from prosecution. The law in the UK is forcing me to consider dying before I am ready. It should be changed so that I, and others like me, can know that if our suffering does become unbearable we can choose an assisted death.

In conclusion

The meeting proved to be an excellent opportunity for Parliamentarians to meet the real people who have been affected by our laws around assisted dying, and for people who have accompanied a loved one overseas to die, to meet each other.

The audience expressed their concern about living in a society which forces mentally competent, terminally ill adults to travel abroad, often far earlier than they would wish, to achieve a dignified death.

The meeting concluded with a consensus that Parliament needs to address this issue - sooner rather than later.

Supporters of our campaign outside Parliament after the meeting

Members make their voices heard: Lisa's story

Sometimes even a difficult start can lead to a positive result for our campaigns. Here is a good example of how it is done.

Lisa Cook, 40, from Huddersfield, has been campaigning for Dignity in Dying for a long time. She has written to her Labour MP, Barry Sheerman, three times trying to get his support for a change in the law.

Lisa has the gene for Huntingdon's Disease and is likely to develop symptoms of the disease after she turns 50. The disease can lead to degeneration of muscles and some people die from choking on their own saliva. Lisa wants the right to choose when and how she dies.

> "I like to think that I have lived my life with dignity and I would like to be able to die with dignity."

Unfortunately, Barry Sheerman MP replied to say that he can't support her campaign due to his religious belief. He said: "I appreciate that this may be difficult to accept for those affected by terminal illness, but the sacrosanct nature of life is a fundamental pillar of the Christian faith, which I do not believe can be compromised."

Despite this setback, Lisa still managed to gain press coverage to widen awareness of our campaign. By sending a copy of the MP's letter and giving an interview to her local newspaper, the Huddersfield Daily Examiner, her story made front page news.

She told the newspaper: "I fully respect the right of people to hold religious views. However, I do not think Mr Sheerman should impose those views on his constituents. Mr Sheerman was a supporter of the Iraq war, in which thousands of lives were cut short as a result of practice that facilitates the termination of life."

GIVE ME RIGHT TO DIE

Mum's 'final choice' plea

The newspaper also covered the story in its editorial and ran a poll on the subject. The paper received a record number of responses to the poll with 88 per cent in favour of a change to the law. The editorial said: "It would be a hard-hearted individual who could not feel for her in her period of dark despair." It continued: "It is cruel and heartless that British law should not only force people to travel abroad if they are determined to end their suffering but also to threaten with criminal prosecution any loved ones who assist them."

Lisa has requested a meeting with her MP

> "I just want answers to my questions about why he has voted in favour of the Iraq War and abortion but won't support Dignity in Dying. Politics and religion should not mix - Mr Sheerman should be representing what his constituents want in Parliament, not basing decisions on his religious belief."

Of course, at Dignity in Dying we know that many of our members have a strong faith, and that for them there is no contradiction between this and their support for greater patient choice.

The coverage in Lisa's local paper also led to stories in the national press, with Lisa being interviewed by The Sun and The Guardian newspapers.

To find contact details for your MP, use this website, www.theyworkforyou.com

Your gift to the future - a bequest in your will

For many people leaving a bequest in their will to a cause they feel strongly about is often the most generous charitable gift of their life. This is particularly true of those supporters whose existing financial arrangements mean that they are not able to contribute as much as they would like to during their lifetimes.

The Book of Remembrance honours those who have left a gift to our cause.

For Dignity in Dying as an organisation, legacy bequests are a vital lifeline which helps us to exist. It would be very difficult to overestimate just how crucial income from our supporters' bequests is to our survival. Often legacies make up more than 40% of our annual income. Gifts in our loyal supporters' wills ensure that we are here from year to year, to campaign for that vital change in the law, which will stop unnecessary suffering at the end of life.

This is why we are asking you to consider mentioning Dignity in Dying in your will now if you haven't already done so. Please remember, during these difficult economic times we are only able to do our work because of the generosity of our supporters, and your bequest could be that final tipping point in our campaign for change.

The MCA: one year on

It is now almost a year since the Mental Capacity Act came into force, giving advance decisions (living wills) statutory power, and introducing Lasting Powers of Attorney. But has the MCA made a difference? If you or a loved one has used an advance decision or an LPA over the last year please let us know what impact (if any) the MCA had for you and your family. Contact Davina Hehir on **020 7479 7738** or **davina@dignityindying.org.uk**.

TV company needs help

Dignity in Dying has been approached by a production company making a documentary for Channel 4 about assisted dying for the terminally ill. The documentary makers are looking to talk to people who have already made the decision about how they want to end their life. These people must be clear and unwavering in their decision. If you would like to find out more about this project please contact Davina Hehir on **020 7479 7738** or **davina@dignityindying.org.uk**. Getting in touch will not oblige you in any way to be involved in the documentary.

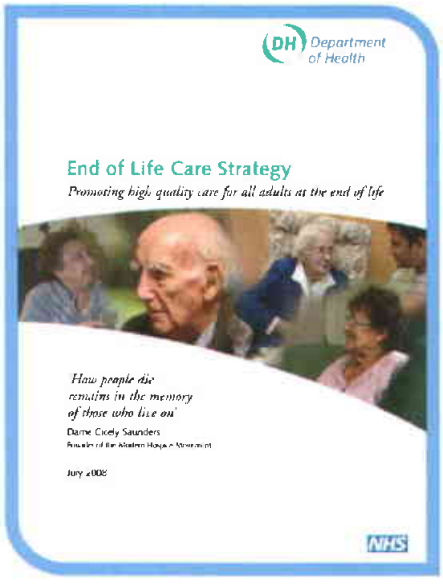
News update

New figures from Dignitas

The Sun newspaper reported on new figures from Dignitas, the organisation in Switzerland that helps people to die. Over 90 Britons have chosen to have an assisted suicide there and in total 868 people have ended their lives at the clinic. Chief Executive of Dignity in Dying, Sarah Wootton was quoted in the paper as saying: "The steady increase in British citizens travelling to Dignitas is further proof the current law in the UK is not working. Until there is a law allowing terminally ill, mentally competent adults the right to choose a medically assisted death, many more people will make this tragic pilgrimage." A few days later The Sun letters page was dominated by letters calling for a change in the law on assisted dying.

Welcome for Government Strategy

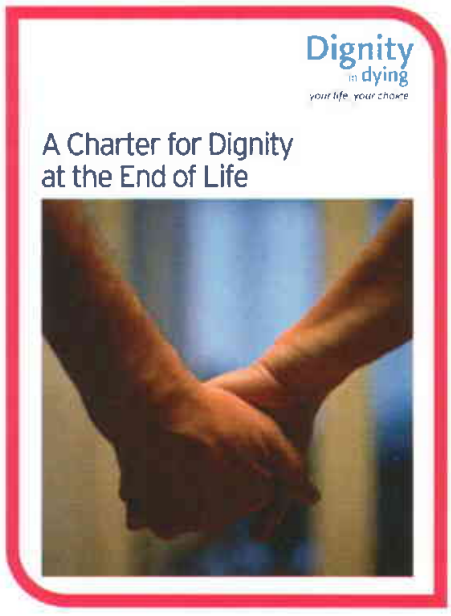
Mature Times covered the story about the long awaited Government strategy on end-of-life care. The strategy has been backed by £286 million to provide high quality care for adults, allowing more people to choose where they die. Sarah Wootton was interviewed for the piece and said: "Implementation of the strategy is key to ending the present postcode lottery in good quality palliative care. If we are to see real change, both central Government and PCTs must be committed to delivering on the strategy."


DH Department of Health
End of Life Care Strategy
Promoting high quality care for all adults at the end of life
How people die remains in the memory of those who live on
Dame Cicely Saunders
NHS

Sarah also had an article published on The Guardian's website, welcoming the End of Life Care strategy. She said: "Today's announcement on end-of-life care marks a significant shift in thinking on how terminally ill people should be treated - that they should be seen as individuals - when they are nearing the end of their lives. If we are to ensure that all people have what they consider to be a dignified death, then they must have equal access to quality care, choice about where they die and when to stop treatment, and control not just over planning for death and pain relief but, ultimately, how and when they die."

Positive press for Charter

There was a lot of positive national and local press coverage of the launch of Dignity in Dying's Charter for Dignity at the End of Life. The BBC website covered the story, explaining the broad remit of the Charter: "In addition to allowing terminally-ill, mentally competent patients control over their death, the charter calls for "end of life" plans for all patients, increased awareness of the right to refuse treatment and better resources for palliative care." The BBC also highlighted Lord Warner's support for the Charter for Dignity at the End of Life. He told them: "This Charter is all about enabling people to exercise personal choice, and one part of that - for a minority of terminally-ill people - is when things get absolutely too much, their pain threshold has been breached and their quality of life is very poor, having the choice of an assisted death." However, Lord Warner emphasised that the Charter is about more than assisted death, saying: "We would like to see the Government responding to all points in this Charter."



World news

USA: Initiative makes it to November ballot

More than 300,000 people have signed a petition to support a "Death with Dignity" initiative in Washington State, USA. This will mean that it goes forward to a ballot for the electorate to vote on at the same time as the Presidential election in November.

If the initiative wins the vote, doctors will be allowed to write prescriptions for mentally competent, terminally ill patients.

Italy: Father fights for daughter's rights

An Italian father won the right to remove a feeding tube from his 37-year-old daughter, who has been in a coma for 16 years.

A Milan appeals court decided that the coma was irreversible and that the decision should be based on the patient's own wishes, as recalled by family and friends.

Critics said the appeal court ruling opened the way for euthanasia. The prosecution, which opposed his decision, has 60 days to appeal.

Umberto Veronesi, a renowned cancer specialist, called the judgment a victory for "the self-determination of the individual".

Letters to the editor

Please send us your response to any of the articles in this issue of Dignity in Dying News. You can also write to us about other matters that readers may be interested in, for example, any local press coverage, correspondence with MPs or doctors, or reasons why you support our campaign.

We would also like to hear from you if you have news stories or ideas for features you would like us to cover in the newsletter.

Please send letters to Davina Hehir at **davina@dignityindying.org.uk** or post them to Dignity in Dying, 181 Oxford Street, Marylebone, London, W1D 2JT or fax to 020 7287 1760.

If you wish your letters to remain anonymous, please state this clearly.

Czech Republic: Parliament debates bill

An Independent Senator in the Czech Parliament has proposed a bill that would allow doctors to assist certain patients to die at their request and end life support if a "living will" gives these instructions. Vaclava Domšová told the Prague Post: "Most politicians are afraid to back this topic, I, on the other hand, prefer action to words and have decided to force my colleagues to debate the issue."

Shadow Health Minister David Rath, a doctor, supports the bill. He told the newspaper: "It's not just about pain. No amount of morphine is going to help someone who has a disfiguring tumor on their face and only six months to live. Such people should have a choice to end their life with dignity if they want to." He stressed that it should be an individual decision and doctors should help patients who meet all criteria to make an informed and free choice.

The bill proposes that a patient would have to wait at least four weeks until an assisted death could be carried out. During that time, their doctor would have to consult with colleagues to be sure that no option has been overlooked. At the same time, the doctor would have to discuss the situation with the patient repeatedly to ensure that the patient is fully aware of the situation and stands by his or her decision.

Spot the Opposition

It is vital that Dignity in Dying responds to letters in the press or information on websites written by people campaigning against us. These articles are often misleading and discredit our campaign. If you come across any opposition, please let us know, so we can respond.

We recently spotted a briefing by an All Party Parliamentary Group (APPG) on Dying Well, which condemns our Charter and gives incorrect information about Debbie Purdy's case.

It refers to the Judicial Review that Debbie has secured, and says: "The lady in question is not terminally ill: she is suffering from a relapsing remitting chronic illness - multiple sclerosis - which progresses but may not become life-threatening for years."

In fact, Debbie has the primary progressive form of multiple sclerosis (MS), not the relapsing remitting form of the disease. This means that she will have no relapses and her condition and health are steadily getting worse. The recent developments in treating MS only work on the relapsing remitting form of the disease, so she is unable to benefit from them. Debbie made this very clear in the statements issued on her behalf by Dignity in Dying and in the media interviews she gave.

The briefing also refers to Dignity in Dying's Charter for Dignity at the End of Life as "A Deadly Charter", saying it "wraps up a controversial proposal to legalise euthanasia inside a package of measures about increasing choice and care at the end of life".

Yet the group states: "Our website exists in order to publish accurate and reliable information about the care of the dying and about the dangers of legalising what is being euphemistically called assisted dying, meaning euthanasia or assisted suicide."

Spot the links

The APPG on Dying Well has ties with the campaign group, Care Not Killing (CNK), which in turn has strong links with the Christian Medical Fellowship. Dr Peter Saunders, CNK's Campaigns Director is also General Secretary of the Christian Medical Fellowship, which, "exists to unite Christian doctors to pursue the highest ethical standards in Christian and professional life and to increase faith in Christ and acceptance of his ethical teaching".

CNK states that their arguments are in no way based upon religious beliefs and values, however, Peter Saunders' quote suggests otherwise.

Saunders advises: "Christian doctors need to play a key role in this debate; and they will do so most effectively by learning to put what are essentially Christian arguments in secular language."

http://www.cmf.org.uk/literature/content.asp?context=article&id=1792.

Of course, everyone has a right to their own view on this debate, and we recognise that religious belief is one of many factors that may help form each individual's opinion on assisted dying. Indeed, many people with a faith are fully supportive of a change in the law on assisted dying. However, it is unacceptable for people who are opposed to assisted dying on religious grounds to hide the real basis of their opposition.